



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

**Agency Information Collection Activities; Submission to OMB for Review and Approval;
Public Comment Request**

Action: Notice

Summary: In compliance with section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995 (44 U.S.C. Chapter 35), the Health Resources and Services Administration (HRSA) will submit an Information Collection Request (ICR) to the Office of Management and Budget (OMB). Comments submitted during the first public review of this ICR will be provided to OMB. OMB will accept further comments from the public during the review and approval period. To request a copy of the clearance requests submitted to OMB for review, email paperwork@hrsa.gov or call the HRSA Reports Clearance Office at (301) 443-1984.

Information Collection Request Title: Organ and Tissue Donor and Recipient Life Stories Form (OMB No. 0915-xxxx) - NEW

Abstract:

HRSA's Division of Transplantation (DoT) is the primary entity in the Department of Health and Human Services (HHS) responsible for the Organ Transplant Program established under

the National Organ Transplant Act (Public Law 98-507, codified at sections 371- 377D of the Public Health Service (PHS) Act). Section 377A of the PHS Act authorizes the Secretary of HHS to establish a public education program to increase awareness about organ donation and the need to provide for an adequate rate of such donations. In brief, DoT's responsibilities are two-fold: 1) to provide oversight and guidance to the national organ transplant system in the U.S. including monitoring the Organ Procurement and Transplantation Network and the Scientific Registry of Transplant Recipients, and 2) to implement a program of public and professional education and outreach aimed at increasing the number of organ donors in this country. Many preventable deaths occur each year because of a staggering imbalance between the supply and demand for donor organs. As of March 2013, the national transplant waiting list exceeded 117,000. In 2011, the total number of deceased and living organ donors was only 14,145. These donors enabled 28,538 patients to receive a transplant while 6,693 died waiting. Without successful interventions to increase donation, the disparity between need and supply is likely to be substantially exacerbated, resulting in more unnecessary deaths.

Organdonor.gov is DoT's primary mechanism for providing the public with information about organ donation. Among the most visited pages on organdonor.gov are the donor and recipient life stories which in a recent evaluation study were shown to raise interest on the topic and, more important, persuade people to register as organ donors. To expand this component of organdonor.gov, DoT proposes to develop an application to give organ recipients, living donors, and donor families the opportunity to voluntarily submit their stories to DoT via a standardized online form. The online form will be posted on organdonor.gov and will collect demographic and contact information, the individual's donation/transplant story up to 500 words, a high

resolution photo, and a signed authorization. The standardized, electronic form will increase HRSA staff's ability to process those stories more efficiently. In addition to enabling story submission, the online application process will make the donor and recipient life stories posted on the site searchable by the public to enhance public viewing and understanding of the organ donation process. Submission of a story and completion of the form is voluntary. Overall, this application has the potential to strengthen DoT's outreach efforts and increase organ donation registration in the United States.

Burden Statement: Burden in this context means the time expended by persons to generate, maintain, retain, disclose or provide the information requested. This includes the time needed to review instructions, to develop, acquire, install and utilize technology and systems for the purpose of collecting, validating and verifying information, processing and maintaining information, and disclosing and providing information, to train personnel and to be able to respond to a collection of information, to search data sources, to complete and review the collection of information, and to transmit or otherwise disclose the information. The total annual burden hours estimated for this ICR are summarized in the table below.

The annual estimate of burden is as follows:

Form Name	Number of Respondents	Responses per Respondent	Total Responses	Hours per Response	Total Burden Hours
Donation/ Transplantation Life Story Submission Form	100	1	100	0.68	68
Total	100	1	100	0.68	68

Addresses: Submit your comments to the desk officer for HRSA, either by email to OIRA_submission@omb.eop.gov or by fax to 202-395-5806. Please direct all correspondence to the “attention of the desk officer for HRSA.”

Deadline: Comments on this ICR should be received within 30 days of this notice.

Dated: March 14, 2013

Bahar Niakan

Director, Division of Policy and Information Coordination

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